

2003 Evaluation of People with Developmental Disabilities Moving from Developmental Centers into the Community

Submitted by:



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EXECUTIVE SUMMARY

In response to the Legislature's special obligation, to ensure the well-being of persons with developmental disabilities who were relocated from Developmental Centers (DC) to the community, the College of Continuing Education (CCE) at California State University, Sacramento (CSUS) conducted the following study under Interagency Agreement (IA) HD029004. The study includes all persons moved as a result of the *Coffelt v State Department of Developmental Services (DDS)* settlement agreement (1993), as well as any persons that subsequently moved and met the terms of the Coffelt agreement.

The objective of the study is to track the quality and the appropriateness of care received by persons with developmental disabilities and measure outcomes in their health, safety, quality of life, integration, choice, and consumer satisfaction. Also, the study interviewed family and advocates to determine their satisfaction with the consumers' care and initiated a pre- and post study of 26 developmentally disabled persons residing in one of five Developmental Centers who are expected to return to the community prior to or during the next data collection period.

STUDY METHODS

CSUS was given a list of 2,319 consumers; 2,200 were found and interviewed and 119 found but not interviewed. The latter group was not interviewed because they had been returned to a Developmental Center (DC), incarcerated, sent to an acute care or psychiatric hospital, were homeless and living on the streets, deceased, reported as a closed case, or refused to answer. The reason for not interviewing those who were returned to a DC, incarcerated, homeless, or in an acute care or psychiatric hospital is that they are not receiving regular Regional Center (RC) services and to report data as if they were receiving those services would have been misrepresentative.

The majority of the data were collected from the staff at the consumers' place of residence. In cases where the consumer was living independently or in a family home, the data were collected from the consumer, a relative, supportive living services worker, or a case worker. The consumers' survey was conducted with the consumer if he or she was able to respond. Two staff responded for consumers unable or unwilling to participate in the consumer survey. The advocate (parents, relatives, guardians, and conservators) survey was conducted by telephone except in one case where the respondent asked that the survey be mailed. All data were entered into a database and analyzed using a spreadsheet or the Statistical Package for the Social Sciences (SPSS). Since this is a benchmark survey, the study is largely a descriptive one.

Problems of Measurement

The consumers studied are not one population, but several. The reasons are that the study population's disabilities vary widely and the causes of those disabilities are complex. Consequently, the kind of care the consumer receives and the way the consumer responds to that care cannot be studied as one group. Instead, the population had to be divided into subgroups so that reports of their well-being and satisfaction are not distorted by the wide variance in their capabilities.

The problems of measurement are discussed in detail throughout the report. There are few standardized achievements against which consumer behavior or progress can be measured. Except for items that can be verified by the records, the staff is speaking "for the consumer." Basically, the respondents' opinions and viewpoints are very often subjective, rendering the data somewhat unreliable.

Also, there are built-in assumptions in past studies that have not been tested. The notion of integration is difficult for a population that is never truly integrated into the community. What has been measured in the past is the number of times a consumer has community outings. While the number of times traveling into the community may be a very positive aspect of the consumers' lives, it does not necessarily measure integration.

SPECIFIC FINDINGS

The findings of this research project are predominately positive. Conversations with long-time visitors indicate that the consumers they have interviewed over the years are living improved lives. The majority of the study population:

- Live in clean and pleasant environments and attend day programs. Although still a minority, some day programs offer nothing less than exhilarating experiences for consumers at all levels of physical and behavioral functioning.
- Like their living situations and enjoy their day programs. Consumers living with their families are more likely to report being happy and satisfied with their lives and consumers living independently are more likely to report greater opportunities for making choices and decisions.
- Regularly attend events in the community.
- Are cared for by educated staff who are satisfied with their jobs and like working with the consumers.
- Are in good health and receive the medical, dental, and mental health services they require.
- Have an up-to-date IPP that is useful to the staff.
- Have experienced few mental health, legal or personal abuse events.

Although the majority of the consumers are well-adjusted to their community homes, the data show that some negative occurrences were uncovered by the visitors. Probably the most critical are the 3.3 percent of the study population that are not living in a community facility or a supported or independent living situation. These include consumers that are incarcerated, returned to a Developmental Center, homeless, or in an acute care or psychiatric hospital. For whatever reason, these consumers are not in a stable situation.

Another 0.7 percent refused to be interviewed. It is imperative that the next year's visitors' procedures reduce that unacceptable statistic because some of these consumers have refused in the past. While the visitors cannot force the consumers or their relatives or guardians to participate, the research staff must develop better methods for obtaining information directly or indirectly.

Scattered by nonetheless troubling findings included:

- Unreliable life satisfaction data reported by staff for nonverbal consumers. It appears that staff responses inflate consumer satisfaction.
- The concept of integration used in this study is not descriptive of the consumers interaction with the community. While consumers go out into the community, very few are integrated into the everyday lives of persons without disabilities either at school, work or day program. For example, 43.5 percent of the study population requires constant supervision, 51.2 percent do not use words, and 25.6 percent do not initiate interaction with others under any conditions. In fact, some consumers may be leading separate but unequal lives in the community because the public sometimes resents sharing public places with the consumer population. This is not an argument against introducing consumers to the community, it is an argument for improving the description and measure of the consumers' community experiences.
- Some staff reports that transporting consumers to and from day programs poses some significant risks. Staff claims that there is no adequate supervision on board the vehicles, that the drivers are unable and ill-equipped to deal with medical and behavioral emergencies. As important, some consumers are transported long distances to their day program. They arrive home exhausted and sometimes unwilling to go for the long ride day-after-day.
- Some staff has problems with staffing requirements at the day programs. They claim that the day program staff are not equipped to care for medical and personal hygiene problems that sometimes arise during the day.
- Some day programs are little more than poor baby sitting situations.
- Consumers living independently are more likely to report that they are unhappy and dissatisfied with their day programs and more likely to live in sub-standard housing.
- Consumers living in their relative or guardian's homes are more likely to live in unsafe neighborhoods.
- The DC sample reported a greater satisfaction with their lives than the consumers living in the community. They reported greater access to friends and more frequently opportunities to visit them and to be visited by

them. This may be an artifact of the data collection instrument and will be discussed later.

- While the majority of the consumers' medical needs are met, staff continues to have difficulty obtaining the services of medical specialists and some psychiatric services.
- Visitors reported anecdotal incidents of abuse that may or may not have occurred in the past. For example, they were told that a consumer's school reported the consumer's father for abuse and that one consumer reported that she had been raped but later admitted it was a consensual act that she was afraid to admit.
- If staff is excluded as the consumers' advocate, only about one-third of the consumers have someone looking after their best interests. This is particularly true for older consumers who have outlived their parents and other close relatives.

OVERALL FINDINGS

As a group, consumers are well cared for, living in positive environments, and receiving the services they need. According to staff, the consumers are satisfied with their lives and making progress on their life goals.

Of some concern is the minority who have been reported as abused, unwell, or unhappy. Of special concern are those who have been returned to the DCs and who are homeless and incarcerated. The question that should be asked is if the community can improve their services to that population.

Also, the follow-up of the consumers might begin to place more emphasis on their day programs as consumers spend a large part of their day in those environments. The questions that need to be asked concern the cooperation between residence and day program staff and the extent to which the day program works with the consumers to achieve their IPP goals.

DESCRIPTION OF THE POPULATION

The description of the population includes their demographic characteristics and status of their disabilities. Their disabilities include the level of mental retardation and secondary diagnoses such as physical and mental disorders, diseases, and autism.

Demographic Background

The study population is predominately male, Caucasian, and never married. The average age is 44.4 years. The majority of the study population do not have a conservator. Compared to previous studies, the current demographic statistics for the consumers' racial and ethnic background indicate that the percent of minorities is increasing.

Status of Disabilities

Over 97 percent of the study population is diagnosed as mentally retarded, a proportion similar to that found in previous studies. The most frequent secondary diagnosis is communication disorders. Of those diagnosed with communication disorders, 80 percent were diagnosed as major disabilities. Other frequently diagnosed disabilities include aggressive behaviors, seizures, ambulatory disorders, and self abuse.

Living Situation

The majority of the study population live in Community Living Facilities (CLFs) or Intermediate Care Facilities for the Developmentally Disabled (ICF DD) either nursing (N) or habilitative (H). The visitor's exterior and interior assessments of the housing indicated that the majority is in good condition, in safe neighborhoods, attractive and clean. The condition of the housing was analyzed by subgroups of consumers. It was found that consumers living independently were the most likely to be living in housing in poor condition, that consumers living in family-owned housing were the most likely to be living in unsafe neighborhoods, and that consumers living in CLFs and ICF DDs (4-6 beds) were the most likely to be living in unattractive housing.

The majority of the consumers live in households with at least one other disabled person. On average, the consumers have 5.18 friends and 1.63 family close family members. The averages for friends and close family members are somewhat misleading because 24.4 percent of the study population has no friends and 45.5 percent have no close family members.

Consumers average 4.46 telephone contacts with friends or relatives, 2.56 visits, and receive 0.47 pieces of mail a

month. Once again, the percents are somewhat misleading because 62.7 percent of the study population receive no telephone calls, 60.3 percent no visits, and 80.1 percent, no mail.

On average, the households in which the consumers live are staffed by 5.18 full time and 1.63 part time persons. The visitors rated 90.2 percent of the staff-consumer interaction as very or fairly warm. Less than 3 percent of the interaction was rated as cool.

Staff Characteristics

The data show that the average age of the caretakers is 41.7 years, quite close to the average age of the consumers, 44.4 years. The staff are 74.6 percent female and 65.0 percent minority, exactly opposite of the demographics of the consumer population.

The staff is well-trained. Only 3 percent have less than a high school diploma and over 77 percent have some college or a college degree. Over 92 percent said they believe they have sufficient training. Those who would like more training mentioned disaster planning, stress management, AIDS awareness, and caring for consumers with disabilities such as diabetes and mobility problems. As a group, the respondents earned a total of 1,148 credentials. The most frequently mentioned was a Qualified Mental Retardation Professional (QMRP). Other credentials mentioned included Licensed Vocational Nurse (LVN), Registered Nurse (RN), Certified Nursing Assistant (CNA), Psychiatric Technician (PT), and various administrative credentials.

The majority of residence staff receives benefits on the job. The most frequently mentioned was vacation pay followed by health insurance and paid sick leave. Over 50 percent of the staff work more than 40 hours a week. Their salaries fall into three groups; hourly (\$11.77), monthly (\$2,035) and annual (\$42,446).

The majority of the staff has worked with persons with developmental disabilities an average of 8.9 years and with the specific consumer 3.1 years. Turnover between staff and/or consumers appears to be quite high because 60.8 percent have worked with persons with developmental disabilities and 57.9 percent with the specific consumer for less than one year. Job satisfaction is quite high, however. The staff rated their satisfaction with their job 4.75 on a 5-point scale with 5 representing the greatest satisfaction. On the same scale, they rated their satisfaction with the consumer 4.77.

The IPP Planning Process (IPP)

The IPP was present in 88.3 percent of the households visited and, of those present 92.0 percent were current. A current IPP was more likely to be found in agency homes, such as foster and adult care households and in CLFs with 4 to 6 beds. Over 90 percent of the consumers were present at the IPP and, of those attending the conference 41 percent contributed to the planning process. About 52 percent of the consumers' advocates were present at the conferences and contributed at least somewhat.

The IPP goals most frequently listed included independent living skills and reduction of behavior problems. According to the staff, 97 percent or more of the consumers were working toward their goals and 74 percent or more were making some progress.

The residence staff was asked to list five of the consumers' greatest needs. While they mentioned many of the goals listed on the IPP, they were more likely to concentrate on nurturing or caring for the consumers. For example, they mentioned consumers' needs as loving and caring, supervision and safety, and more frequent family contacts more often than the IPP goals. This may be because the training and background of the staff is predominately in the areas of care skills.

Although staff had some complaints about the caseworkers, they rated them as 3.70 or higher on a 4-point scale with 4 representing the highest rating. The case worker characteristics rated included helpfulness, availability, knowledge of the consumer, and satisfaction. The characteristic rated lowest was availability.

School, Work and Day Program

Only 2.5 percent of the study population receives academic instruction. The majority attends in-home classes, classes with other students with disabilities, and with persons that speak their language.

About 85 percent of the consumers attend work or a day program. Of the consumers, about 13 percent work at a paid job. During the day, consumers at work and day programs come in contact with at least one person with no disabilities and persons that speak their primary language.

Of the consumers that work, over one-half work less than 10 hours a week and are paid less than minimum wage. The majority are transported to work by an agency-owned vehicle. Consumers living in family-owned homes are much more likely to participate in community-based employment.

With respect to day programs, the staff reports that consumers are engaged in appropriate activities and are making progress on the tasks assigned to them. Visitors rated staff involvement lower than they rated the day programs' structure and planned activities. The visitors reported a wide range in the assessments of the day programs. They found that some day programs were innovative and creative, able to enhance the consumers' daily living skills while others appeared to serve as babysitting operations.

CDER Scores

The Client Development Evaluation Report (CDER) assesses the consumers' demonstration of daily living skills (SDD) and challenging behaviors (CB). The SDD and CB scores are reported in two ways, a mean score on a 5-point scale with 5 representing the highest score for each item on the scale and a composite score representing the entire list of SDD and CB items.

Of the SDD scores, the items that rated highest are use of both hands (4.45) and eating independently (3.99). The item scored lowest is taking medications independently (1.55). The composite scores indicate that there is a positive and linear relationship between behaviors such as aggression, sexual disorders, substance abuse, and diagnoses of autism and mental illness. As the level of daily living skills increases, the proportion of consumers diagnosed with these disorders increases, also. As expected, the lowest SDD scores are associated with consumers diagnosed with physical disabilities.

None of the consumers in the study population exhibited extremely high CB scores. Disruptive behavior exhibited the highest mean, 2.37. As expected, the proportion of consumers with high composite CB scores increased for those diagnosed with aggression and self-abuse. The relationship between CB scores and physical disabilities indicates that physical disabilities do have an impact on the consumers' ability to exhibit challenging behaviors. The lower the proportion of physically disabled, the higher the CB score. The relationship is not strong between high CB scores and sexual disorders or substance abuse, however. The CB scores are related to autism and mental illness. The proportion of the latter diagnosed groups increases as the CB scores increase.

Health and Medications

The health of the majority of the study population was reported as good or excellent. The staff found medical and dental care easy to find, although dental was not as easy to find as medical. It was more difficult for staff to find specialized medical services, however. For at least 96 percent of the consumers, the quality of care received was rated as good or very good.

Although the majority of consumers are in good health, 30 percent were described as having a significant weight gain or loss during the past year. Of those exhibiting this condition, weight gain or loss had a negative impact on 30 percent of the consumers.

Mental Health Services and Legal Concerns

According to staff, it is slightly more difficult to find mental health services but when those services are found, the staff rated the quality good or very good. The majority of the consumers needed medications monitoring.

Crisis intervention services were requested for about 3 percent of the study population. The most frequently used services were supplemental supports and calls to the Regional Centers.

Less than 2 percent of the study population perpetrated a crime and less than one percent was the victim of a crime. The most frequently committed crimes by a consumer were assault, stealing, and substance abuse. The most frequent illegal acts committed against a consumer were assault and larceny.

The Consumer Survey

Consumers who were able and willing, responded to this survey. Two staff responded for consumers who were unable or unwilling to communicate.

Of the life satisfaction and choice-making questions, the consumers scored the most positive responses for living at their residence, liking the staff at the residence, continuing to live at their residence, attending their day program, liking the staff at the day program, continuing to attend their day program, and being helped to go into the community. The most negative responses were for finding someone to talk to when lonely, feeling lonely, deciding how to spend money, and visiting friends as often as they like.

A comparison of staff responses to the surveys that could not be answered by the consumers shows that staff within the same household have a very different view of the consumers' view of life and satisfaction. When the scores were run for each staff respondent, not one of the means were the same for any one question.

The data were run by living situation as that variable was a good indicator of the consumers' demonstrated daily living skills and, to a lesser extent, their challenging behaviors. The data show that consumers in independent living situations are more likely to have the lowest scores, particularly on items concerning happiness, loneliness, and satisfaction with their residence and day program and higher scores on choice and decision-making. Consumers living in family-owned homes had the highest scores on almost every issue.

The data were rerun once more excluding surveys in which staff responded for the consumers. Differences in the scores occur between (1) feelings and likes and (2) decision and choice making. When the staff-answered surveys were removed, scores for decision and choice-making increased indicating that the consumers left in the database were better able to perform these items and articulate that they could. On the other hand, scores for feelings and loneliness decreased indicating that staff may have overstated these items.

The DC Sample

Twenty-six consumers were interviewed at 5 Developmental Centers (DCs). The purpose of these interviews was to collect benchmark data for a group of consumers who are expected to enter the community prior to or during the next data collection period. As a group, they have a mean age of 37.7 years, are predominately Caucasian, and never married. Almost 58 percent are diagnosed as severely or profoundly retarded. Compared to the study population, the DC sample is younger, more likely to be a minority, diagnosed with lower levels of mental retardation, and have higher levels of aggressive, self-abusive, mental illness, communication, and sexual disorders.

The DC sample has less privacy and more contact with persons outside their residences than their counterparts in the community. In part, contacts outside their residence are very likely to be other consumers on the campus of the DC, making the pool from which consumers can select friends much larger. They live in larger housing units and have a greater number of roommates. Staff is well-trained, better paid, and have more benefits than staff in community facilities.

The health of the DC sample is rated somewhat higher than that of the study population. According to DC staff medical, dental, and mental health services are very easy to find and of good quality. Compared to the study population, the DC sample is more likely to take medications for general ailments than for psychiatric disorders or seizures.

The DC sample is more likely to rate their satisfaction with life higher than the study population. The items rated higher by the DC sample were both those inquiring about feelings and choice or decision-making.

Advocate Survey

Advocate surveys were completed for 38.7 percent of the study population. Of those surveys, 54.6 percent were completed by the consumers' mothers and 78.9 percent completed by a relative, including the mother. It should be noted that the data in this survey do not represent the majority of the consumer population, especially those that are incarcerated, living on the streets, or in acute care of psychiatric hospitals.

Each respondent rated the care and services received by the consumers in community facilities superior to those received in the DCs. Over 80 percent said they would probably or definitely not want their loved one returned to the DC.

Overall, the respondents were pleased with their relationship with the staff in community facilities. The one exception is their belief that staff does not pay enough attention to the advocates' opinions. The advocates' ranked their preferences for the consumers as independence, safety and well-being, work, and social, in that order. The preference for health/medical and developmental and educational skills tied for last place.

LOOKING TO NEXT YEAR

Level 2 Alerts

The level 2 alert sheet needs to be revised. The revisions should include but not be limited to:

- Incorporating the full text of the question, the question number, and the page number for each item.
- Standardizing the definition of close friends and other terms that are ambiguous.
- Including significant weight gains and loses only if they are negative.
- Discussing the possibility of including other items that may suggest problematic situations.

Revising the Survey Instrument

In general, the survey instrument must be revised so that there are fewer visitor errors. This year, each visitor was trained by the project director and given an instruction manual and not remembering their training instructions. Careful editing of the surveys indicated that the visitors were not using the manual. This observation does not undermine the hard work of the visitors. It is more of a testament to the complexity of what we are doing and the conditions under which the surveys are conducted. Consequently, survey revisions (already begun) will include a more careful wording of each question, careful definitions of terms, and full responses instructions included with each question. Along with these revisions, the training sessions will be conducted and the surveys will be edited before the visitors are paid.

Definition of Terms

Discussion will be held with DDS and RC professionals to identify expectations for consumers so that measures for integration, happiness, loneliness, and other "subjective" terms can be developed.

Day Programs

The day programs need to be more carefully scrutinized. Next year's report should be able to make the distinction between creative programs that strive to develop the consumers' abilities and baby sitting operations that cater to the consumers' disabilities.

Medications

The data for medications should be limited to the number of medications and the purpose, if identified, of each. The categories of medications should include psychiatric, prescription medications for physical ailments, over-the-counter medications, and PRNs. The doses given should be eliminated because the statistical manipulation of these numbers does not provide a meaningful statistic.

Staff Respondents

Staff responses for consumers on the consumer survey should be eliminated. Consumers who can respond should be surveyed. Another method should be devised to determine whether consumers who are profoundly disabled are happy, lonely, or satisfied with their lives.

Visitor Procedures

Procedures should be revised for collecting information about consumers who refused to respond to the survey. This year, visitors noted that they had not been able to "get to see this person" in several years. If that is true, the project must develop a method to ensure that these consumers are well and receiving the services they need. It is our goal to reduce the number of refusals in next year's report.

Eliminating/Adding Questions

There should be an investigation of questions that can be dropped. For example, an examination of past reports reveals that the questions on staff training indicate that just about everyone is trained on just about everything and

very few think they need more training. Questions offering little new information will be identified and a more stringent approach will be used to collect more meaningful information.

More Detailed Analysis

Finally, this report asserts that there is not one study population, but many. The research team believes that the analysis of the data collected can be improved greatly by the development of consumer categories. The research team will continue to seek assistance to develop these categories. Suggested categories can be based on the consumers' physical and mental health, their specific disabilities, or their level of functioning. One thing was discovered this year that there are no "pure" categories and that we must work to develop a system of stratification that can help us better understand the consumer population. The report must, however strive to be less and less ambiguous about the persons for whom the results are being reported.